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Parental Bereavement and Hospice Participation: An Evaluation of the Edmarc Hospice Program

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Parental Bereavement and Hospice Participation: An Evaluation of the Edmarc Hospice Program

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TABLE OF CONTENTS

	Page
ACKNOWLEDGEMENTS	iv
LIST OF TABLES	v
LIST OF FIGURES	vi
ABSTRACT	vii
INTRODUCTION	2
METHOD	11
RESULTS	16
DISCUSSION	21
REFERENCES	35
APPENDIX	38
TABLES	41

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LIST OF TABLES

Table Page

1. Characteristics of Edmarc, GEI, and FES Subjects 41
2. Means and Standard Deviations of the Grief Experience Inventory 42
3. Means and Standard Deviations of the Family Environment Scale 43
4. Correlations Between Bereavement Factors and Grief Adjustment Indices 44
5. Edmarc Subjects' Mean Ratings of Helpfulness 45
6. Edmarc Subjects' Mean Ratings of the Helpfulness of Edmarc Services 46

LIST OF FIGURES

Figure Page

1. Perceived helpfulness as a function of time interval and service/individual 47

Abstract

The purpose of this study was to examine the relationship between of hospice participation and parental adjustment to the terminal illness and death of a child. Researchers have shown that this form of loss is one of the most stressful and debilitating life experiences (Videka-Sherman, 1982; Sanders 1979). In one study, parents reported significantly higher levels of hostility, anger, and guilt following the death of their son or daughter than bereaved spouses and children reported (Owen, Fulton, & Markusen, 1982). Illness and mortality rates were higher among bereaved than non-bereaved parents (Levav, 1982). Also, hospice patients and individuals providing their primary care have been found to experience significantly less anxiety, depression, hostility, somatization, friction, submission, and dependence than non-hospice participants (Lack & Buckingham, 1978). Subjects for the present study were parents of terminally ill children who participated in the Edmarc Hospice Program prior to their child's death. They were asked to complete the Grief Experience Inventory, or GEI (Sanders, Mauger, & Strong, 1985), a self-report measure designed to assess experiences, feelings, symptoms, and behaviors associated with the grief process; the Family Environment Scale, or FES (Moos, & Moos, 1986), a questionnaire that measures adequacy of family functioning on various parameters; and the Parental Reactions and Perceptions Questionnaire (PRPQ), a list of questions focusing on parents'regarding utilization and evaluation of the Edmarc program. Comparison data were obtained for non-hospice bereaved parents who participated in prior studies (Sanders, Mauger, & Strong, 1985; Mulhern, Lauer, & Hoffman, 1983). It was not possible to obtain complete data sets from applicable studies, therefore, it was necessary to make hospice/non-hospice statistical comparisons via t-tests of relevant subscales of the GEI and FES. No significant differences were found between these two groups. However, 10 of 12 GEI scales indicated more positive grief adjustment for the Edmarc group. The helpfulness of various individuals and public services (e.g., parents, spouse, school system, etc.) during the child's illness and following his or her death was also evaluated. A general decline in perceived support was noted after the child's death, with a significant decrease in the perceived helpfulness of physicians and social services. Statistically significant differences were not found among the subject's helpfulness ratings of the different Edmarc services. However, differences approaching significance were found between long-term follow-up services and those provided during the child's illness, with long-term follow-up services being perceived as more helpful.

Parental Bereavement and Hospice Participation:

An Evaluation of the Edmarc Hospice Program

Parental Bereavement as a Function of Hospice Participation

This study concerned bereavement--grief resulting from a personal loss. Specifically, the adjustment of parents coping with the death of their child was examined. The death of a child has been characterized as one of the most difficult and distressing events that can happen in one's life (Videka-Sherman, (1982). Studies comparing adult bereavement in the death of a spouse, child, and parent, have found significantly higher intensities of grief in parents surviving a child's death-- increased somatic reactions, depression, anger, guilt, hostility, and feelings of despair. (Owen, Fulton, & Markusen, 1982, Sanders, 1979). Levav (1982) found significantly higher mortality rates among bereaved parents. This phenomenon may be related to poorer health maintenance, less attention to personal welfare, and behavioral changes such as increased cigarette or alcohol consumption, in response to the individual's grief.

An important component of the adverse effects of parental bereavement is guilt. Reports of guilt feelings are consistently cited in the literature concerning parental reactions to the death of a child. Rando (1985) discussed parental guilt in terms of role failure--parents blaming

themselves for not being able to fulfill their role of protecting and caring for their child.

Guilt may influence relationships with others as well. Frequently, individuals react to a major loss by displacing feelings of blame and anger onto others who are close to them (Rando, 1985). This displacement may fall on the spouse. Marital difficulties and divorce have been found in 50 to 70 percent of families whose child died from cancer (Kaplan, Grobstein, & Smith, 1976). Rando (1985) cited that spouses may realize different or incompatible grieving styles that may lead to conflict, or contribute to a lack of communication. She also stated the possibility that "spouses can remind one another of the deceased child and may serve as a painful stimulus" (p.21).

Another loss involved in the terminal illness and death of a child may be a loss of control. During the course of traditional hospital treatment of a sick child parents may experience themselves as having little impact--doctors and nurses have taken over the caretaking role. As Martinson and her colleagues (1978) hypothesized, this lack of influence (or control) over the child's illness and treatment may produce feelings of helplessness, characterized by Seligman (1975) as having negative psychological consequences. This helplessness may again produce feelings of guilt--of having failed to protect one's own child.

Thus, researchers have clearly documented that parental bereavement is frequently accompanied by drastic consequences. In attempting to prevent or minimize these negative outcomes, several types of interventions have been used. Few studies, however, have been conducted to assess the utility of these therapeutic techniques. Videka-Sherman and Lieberman (1985) compared parental adjustment following participation in mutual support groups and psychotherapy. Results were disappointing--indicating no improvement in mental health or social functioning in either group. A methodological concern in this study was that subjects were not assigned to the various treatment conditions, therefore, pre-existing differences may have influenced the make-up of the groups, and their resultant response. Also, a no-treatment control group was not included for comparison. Another possible factor in the subjects' lack of measurable improvement may be that these interventions were not initiated until after the child's death. Providing assistance throughout the child's illness and immediately following death may facilitate better recovery.

Anticipatory grief has been characterized as the parents' gradual release of emotional investment from the child (Chodoff, Friedman, & Hamburg, 1964). This process can occur through a realistic understanding of the illness and its consequences, and allows the parent to experience the mourning process gradually, thereby easing and facilitating acceptance of the loss of the child. Although

results have been somewhat inconsistent (Rando, 1986), statistically significant positive effects of anticipatory grief have been found (Sanders, 1979; Rando, 1985).

Other positive influences on bereavement include religiousness and the passage of time. High levels of religiousness and particularly, belief in an afterlife contribute positively to adjustment to the death of a loved one (Aiken, 1985, Vollman, Ganzert, Picher, & Williams, 1971). A general improvement trend has also been found as a result of time--the majority of bereaved individuals have been found to show increased adjustment with the passage of time (Rowe et al., 1978, Lauer, Mulhern, Wallskog, & Camitta, 1983).

In addition to options such as mutual support and psychotherapy, families may elect to participate in hospice programs. The hospice movement emerged in the United States in the 1970's (Aiken, 1985). Hospice as it is now known refers to a philosophy of care for the terminally ill based on:

1. control and palliation of symptoms rather than cure of disease;
2. care given at home or in as home-like an environment as possible;
3. patient autonomy regarding decisions about care;
4. attention to emotional, social, and spiritual needs as well as to requirements for physical care (Osterweis, Solomon, & Green, 1984, p. 249).

Programs may be hospital-based, exist independently, or consist of home-care services. Patients typically are accepted following diagnosis of the terminal stage of illness. A crucial difference between hospice and traditional hospital care is the hospice focus on the alleviation of pain, rather than treatment in pursuit of a cure. Aiken (1985) described the paradox that doctors and nurses deal with in the care of terminally ill patients. Having been trained to save lives, medical professionals may see dying patients as failures. They may seek to avoid the reminder of their inabilities, spending less time with the terminally ill; or feel that their time is better spent in working with patients who stand a chance for survival. Research indicates that staff contact with a patient declines abruptly when an illness is diagnosed as terminal (Aiken, 1985). The patients' sense of isolation and abandonment may, therefore, be further compounded in a traditional hospital setting. Factors that influence the well-being of the patient, also logically impact on concerned family members.

It is important to note that these studies, as in research cited earlier, did not employ random assignment of subjects to treatment groups. It must be recognized that it is often not possible to achieve this type of control in bereavement circumstances. However, this should be taken into consideration when interpreting any differences that may have been obtained by these researchers.

In a home-based hospice program the goal is to assist the family in caring for the terminally ill individual at home, and in coping with the loss. There may be a number of advantages for families who participate in this type of program. First, there is an overall benefit of reduced cost. Martinson and her colleagues (1978) estimated the cost of hospice home care to be one-eighth of the cost of hospital care.

The primary advantages of this type of care, however, are the psychological benefits to the patient and family. Researchers have found that hospice patients and those who provide their primary care experienced significantly less anxiety, depression, hostility, somatization, friction, submission, and dependence than non-hospice patients and providers of their primary care (Lack & Buckingham, 1978, Mulhern, Lauer, & Hoffmann, 1983). Parental guilt ratings over time were significantly lower in situations where the child died at home than when the child died in the hospital (Lauer, Mulhern, Wallskog, & Camitta, 1983). Lauer and associates hypothesized that these differing reactions were due to the parents' increased sense of involvement with the child and his or her care (in the home care situation). This finding of an increased sense of involvement and decreased guilt is congruent with the previously cited research focusing on helplessness and control. Through hospice participation parents can gain a sense of being needed, of assisting with and thereby having some control

over the illness situation (Martinson et al., 1978; Lauer, Mulhern, Wallskog, & Camitta, 1983).

An important factor in positive adjustment following the death of a child has been found to be the presence of an ongoing support system throughout the illness and after the death (Spinetta, Swarner, & Sheposh, 1981). Although the support of others is of crucial importance during the course of bereavement, it is often not available. Friends and relatives may be uncomfortable discussing a child's illness and death, or may feel that the parents need to be alone or shouldn't be reminded of their situation. They may be afraid of "saying the wrong thing", and subsequently, say nothing. In addition to providing medical assistance, hospices emphasize the provision of emotional support to patient and family.

A final component in bereavement is the passage of time. Although time has been found to positively influence resolution of bereavement, regardless of intervention, research indicates that hospice participants recover faster than non-hospice participants (Lauer, Mulhern, Wallskog, & Camitta, 1983).

The present study involved a particular hospice--the Edmarc program in Suffolk, VA. Edmarc is a licensed home health agency that provides services to the families of chronically and terminally ill children. It originated in 1978, and offers services including: nursing and medical assistance, respite care, emotional support for the patient

and family, mutual support groups, a baby-sitting registry, a speakers bureau, and training groups for care providers.

The primary focus of this study was the effectiveness of the Edmarc program in meeting its goals of supporting and assisting the families of chronically and terminally ill children. It was anticipated that families who received Edmarc's services would show higher levels of positive adjustment and lower frequencies of maladaptive responses than families who did not receive hospice services.

Qualitative and quantitative information was obtained from the Edmarc clients in order to better evaluate aspects of the program. Client perception of the helpfulness of various individuals, public agencies, and specific Edmarc services--both during the child's illness and following his or her death--were also examined.

It was predicted that the Edmarc services that enable the ill child to remain at home (e.g., nursing care, respite assistance, etc.) would be rated most highly. Furthermore, it was expected that outside support would decline following the child's death--the significance of the physician and the presence of friends and family would diminish. It was anticipated that the follow-up aspects of Edmarc's services would be rated second in helpfulness; due, in part, to the natural inclination of others to subtly avoid the bereaved. Also, since family members are undergoing bereavement of their own, they may not be able to provide support for each

other. Thus, it was expected that Edmarc's support at this time would be even more essential.

Method

Subjects

All of the subjects in this study were parents who had experienced the death of a child. Each of these subjects belonged to one of two major categories: parents who had participated in home health care during the course of their child's terminal illness, and parents who had not participated in home health care (the comparison group).

For the home health care group, questionnaires were mailed to all parents who had participated in the Edmarc Hospice Program prior to the death of their child (a total of 40). Twenty-two responses were received (17 were completed in entirety, 5 were partially incomplete), 5 were returned by the post office due to a lack of forwarding addresses, for a (possible) return rate of 63%.

Due to the availability of hospice and other support programs in this area, it was not possible to obtain a control group of bereaved parents who did not participate in support services solely because of a lack of access. Parents who purposely chose not to be involved in such services may possess different personality and coping mechanisms or access to personal resources that would affect their adjustment, independent of the intervention/no-

intervention variable (Mulhern, Lauer, & Hoffmann, 1983). Therefore, comparison information was derived from prior research studies. Information was obtained from two prior studies of non-hospice bereaved parents that used the same experimental measures as employed in this study. The first was a 1985 study (Sanders, Mauger, and Strong) that involved 192 bereaved parents, and utilized the Grief Experience Inventory. The second study was conducted in 1983, had 20 applicable participants, and used the Family Environment Scale (Mulhern, Lauer, and Hoffmann). Table I presents the general characteristics of these groups in comparison to parents participating in Edmarc.

Insert Table 1 about here

Information was provided regarding the age of the participants, the number of months since the child's death (this information was not available for the Grief Experience Inventory comparison group), and the age of the child at death. The level of religiousness of the Edmarc group was 2.29 (on a scale with "1" corresponding to "not at all religious", and "3" corresponding to "very religious"), indicating a moderate overall level of religious practice. Information was not available regarding the religiousness of the comparison group participants.

Materials

Assessment measures included the Grief Experience Inventory, or GEI (Sanders, Mauger, & Strong, 1985), a 135-item, true/false inventory designed to assess experiences,

feelings, symptoms, and behaviors of individuals during bereavement. Responses were scored into scales relating to prevalence of maladaptive grief responses (such as denial, despair, anger, somatization, etc.). The GEI also includes an index of social desirability. The internal consistency of the GEI scales, as indicated by coefficient alpha values, ranged from .52 to .84. Test-retest reliability was calculated for individuals who had experienced bereavement within a 5-year time span (Sanders, Mauger, & Strong deemed this time span necessary to avoid the confounds of expected changes that typically occur in the early months following a death); the scale correlations ranged from .61 to .87 (Sanders, Mauger, & Strong, 1985). The GEI was found to distinguish bereaved from non-bereaved individuals with a significant level of accuracy, and to discriminate among different kinds of losses. Scales of the GEI were also found to correlate significantly with other inventories (e.g., the MMPI) measuring similar constructs (Sanders, Mauger, & Strong, 1985). The Family Environment Scale, or FES (Moos, & Moos, 1986), is a 90-item test that was used to assess the adequacy of family functioning in various areas (including family commitment and support, expression of feelings, assertiveness and self-sufficiency, school and work aspirations, ethical and religious values, etc.). Test-retest reliability for the FES ranged from .68 to .86 in an 8-week testing interval. The authors found high profile stability over time intervals of as long as one

year, although they were "reflective of changes that occur in the family milieu"(Moos & Moos, 1986, p.20). Internal consistency measures of the different scales ranged from .61 to .78. Moos and Moos also found that FES results correlated significantly with the ratings of trained observers and other similar measures (1986). Also, the Parental Reactions and Perceptions Questionnaire, or PRPQ, developed specifically for Edmarc, was used to obtain quantitative and qualitative information regarding client's perceptions of Edmarc's services (positive and negative), suggestions for improvement, and degree of utilization of different services. It also included a measure of social and instrumental support, and demographic information. Appendix A contains a copy of the PRPQ.

Procedure

Edmarc clients who met criteria for participation were mailed a packet consisting of a letter from Julie Simpson (Director of Edmarc), and a copy of the GEI, FES, and PRPQ. The letter requested involvement in the study, and informed potential subjects that their participation would assist Edmarc in evaluating and improving services. Due to time constraints and the considerable travel distances among Edmarc clients, it was necessary to administer the study entirely by mail. Although this research involved questions that might potentially elicit emotional reactions, it was felt that the established rapport and continued support

system provided by Edmarc would mediate this potential problem.

Non-hospice control data was obtained from prior research. Authors of relevant studies were contacted, and applicable data were procured. Complete data sets for the GEI and FES control groups were not available; it was possible to obtain only the cell means and standard deviations for these groups. Therefore, multivariate analyses could not be conducted, and overall differences between the hospice and non-hospice groups could not be ascertained. Hence, the most appropriate means of determining specific differences in the adjustment characteristics of these two groups was to perform separate two-tailed T-tests on the individual subscales of the GEI and FES. In order to control for Type I errors, Bonferroni's inequality was implemented. The results of the PRPQ were summarized and analyzed separately.

Results

Individual subscales of the GEI were compared via two-tailed T-tests for the Edmarc (hospice home health care) and control (non-home care) groups. Cell means and standard deviations for both groups are summarized in Table 2.

Insert Table 2 about here

No significant differences were found between the two groups on any of the GEI subscales ($p<.05$). However, 10 of the 12 GEI scales indicated more positive grief adjustment for the Edmarc group.

The various subscales of the FES were also compared via two-tailed T-tests for the Edmarc and control groups. Cell means and standard deviations for both groups are summarized in Table 3.

Insert Table 3 about here

No significant differences were found between the two groups on any of the FES subscales ($p<.05$).

Within - subjects comparisons were also conducted for the Edmarc participants, based on the GEI adjustment scale indices. The resultant correlations are presented in Table 4.

Insert Table 4 about here

Higher levels of death anxiety were associated with a greater number of months since the child's death ($r = .52$, $p<.05$). Also, the subjects' level of guilt was found to be

significantly correlated with the child's age at his or her death (r = .52, p<.05). No other significant correlations were found between the bereavement factors (the number of months since the child's death, the child's age at death, the parent's level of religiousness, and the number of months of involvement with Edmarc before the child's death) and the GEI subscales.

The final instrument administered was the Parental Reactions and Perceptions Questionnaire (PRPQ). The first portion of the PRPQ dealt with the Edmarc subject's ratings of the helpfulness of various individuals and community support services (excluding Edmarc) both during their child's illness, and after his or her death. Table 5 presents the subjects' mean helpfulness ratings.

Insert Table 5 about here

Physicians were judged as the most helpful service/ individual during the child's illness, with a mean rating of 2.83. Spouses and other family members (excluding parents) were also given high helpfulness ratings (2.50) for that period of time. The Public Health Department (1.31), school system (1.63), and social services (1.76) were judged as least helpful.

Following the child's death, spouses and friends were judged to be the most helpful (with a mean rating of 2.50); parents (2.45), and other family members (2.39) were also rated highly. The Public Health Department (1.19), school system (1.44), and social services (1.44) were again judged

to be of the least help. The physicians' helpfulness rating dropped from 2.83 during the child's illness, to 1.82 following the death.

A repeated measures analysis of variance was performed to test for significant differences among these variables. A significant time interval by service/individual interaction was found; F (8,128) = 4.29, $p<.001$. Figure 1 presents this interaction.

Insert Figure 1 about here

The simple effects of time interval were computed, indicating that physicians (F (1,128) = 36.64, $p<.001$) and social services (F (1,128) = 6.21, $p<.05$) were judged to be significantly less helpful following the child's death. Main effects for time interval, F (1,128) = 6.07, $p.<05$, and service/individual, F (8,128) = 7.06, $p.<.001$ were also found.

The second major portion of the PRPQ dealt specifically with subjects' perception of Edmarc services. Table 6 presents the mean helpfulness ratings of the various services provided by Edmarc. Since many of the services were not applicable to all of the subjects (and therefore could not be rated by all subjects), a separate column was included indicating the percent of subjects who were provided with each service.

Insert Table 6 about here

Edmarc's services were divided into five main components. Long-term follow-up services were judged as

most helpful, overall, with a general rating of 2.86. All those who were visited by Christmas carolers (77% of the subjects) reported that it was very helpful to them. Bereavement cards received a 2.85 rating (from 91% of the subjects), and continued verbal contact from Edmarc was given a 2.82 rating (all families rated this item).

The quality aspects of Edmarc were ranked second highest (2.84 overall). The professional skill level of Edmarc's staff and the personal, caring aspects of the program were both rated as very helpful.

Services assisting directly with the child's death and funeral received the third highest overall rating (2.78). The presence of Edmarc staff at the child's funeral was described as "very helpful" by all applicable subjects (82% of those who participated in this study). The Edmarc Memorial Service was also highly rated (2.80), as were funeral planning assistance (2.68), and the presence of Edmarc staff at the child's death (2.65). It should be noted that, despite the generally positive response to Edmarc's assistance with funeral planning, several subjects expressed strong disapproval--stating that they felt unnecessarily pressured to participate in funeral planning (before they were ready and willing).

The final two categories analyzed, hospice services during the illness and emotional support components, received identical ratings of general helpfulness (2.66). Edmarc's nursing care (and the 24-hour availability of

services) was judged to be the most helpful of the services offered (2.82 and 2.83, respectively). Other specific services were also rated highly (e.g., speech therapy, with a 3.00 rating), but were only applicable to a small proportion of the subjects. Among the emotional support components, support for the ill child was rated as most helpful (2.76). Support for parents (2.68), and for the other children in the family (2.50) were ranked somewhat lower.

A single factor within-subjects analysis of variance was performed to evaluate the differences among the helpfulness ratings of the Edmarc service categories. The results, F (4,84) = 2.30, $p<.065$, were nonsignificant by a slight margin. It was, therefore, inappropriate to perform further analyses of differences among the various categories. However, the differences approached significance, and may be helpful in guiding Edmarc's staff. The ratings suggest that long-term follow-up may be perceived as more helpful than services and emotional support provided during the child's illness.

Discussion

It was anticipated that subjects who participated in the Edmarc hospice program would show higher levels of adjustment following the death of their child. It was hypothesized that this positive adjustment would result in significantly lower scores on primary grief components as measured by the Grief Experience Inventory (GEI). It was also predicted that hospice participation would positively enhance family functioning after the child's death, as shown by significantly higher scores on the Family Environment Scale (FES). However, GEI and FES scores for hospice participants, as compared with subjects who participated in traditional hospital care, showed no significant differences.

This lack of significance may be related primarily to two factors. The first factor was the difficulty of obtaining control (non-hospice) data, and resultant necessity of obtaining data from prior research. Since the researcher could not gain access to complete data sets with extensive information about the control subjects, it was not possible to perform more sophisticated and thorough comparisons of the groups.

A second major factor involved pre-existing differences between the subject populations. For example, information was not available on the subjects' adjustment level prior to

their child's death. It is possible that individuals who chose to participate in Edmarc's program, and devote the time and energy necessary to take care of their child at home, were more emotionally tied to their child, and possibly, were experiencing greater difficulty in dealing with their child's illness (and their own feelings of helplessness and guilt). Hence, it is possible that the Edmarc subjects may have entered the program at a lower level of adjustment than the non-hospice subjects. Therefore, the lack of statistically significant differences in post-death adjustment scores may actually reflect a significant improvement for the Edmarc subjects (i.e., a greater within-subjects, pre-to post-death improvement). Since Edmarc does not currently obtain information regarding clients' emotional status at the time of their entrance into the program, it was not possible to examine this question. It may be advantageous for Edmarc to routinely administer a questionnaire (such as the non-death version of the GEI) to incoming clients to assess their premorbid psychological status. In this way it would be possible to assess more accurately the impact of Edmarc's services. It also may be helpful for Edmarc to administer the FES prior to clients' hospice participation. In this way, family information would be available to help Edmarc better understand clients' values and family structure.

Client's perceptions of the usefulness of Edmarc's services were an important component of this evaluation.

Their overwhelmingly positive responses suggest that Edmarc provided a valuable service. The overall mean rating of Edmarc's helpfulness was 2.82 (on a scale of 1 to 3, with "1" signifying "not helpful," and "3" signifying "extremely helpful"). Of 22 responses, 19 rated Edmarc as "extremely helpful." The only client to give Edmarc a rating of "1" (i.e. "not helpful") described her dissatisfaction as being related to Edmarc's "... pushing her to plan her son's funeral..." Her son had been diagnosed as being in the terminal phase of cancer at the time that she became involved with Edmarc; however, he had outlived numerous doctors' predictions for his survival. This client further described her extreme and continuing difficulty in accepting her son's death, indicating that her continuing disagreement with Edmarc regarding the consideration of funeral arrangements probably contributed greatly to her low evaluation. Furthermore, the vast majority of Edmarc's clients rated funeral planning assistance as being a highly helpful service. Ratings given to specific Edmarc services will be discussed in greater detail in later sections of this paper.

It is also possible that those who were less satisfied with Edmarc may have been less inclined to respond to the questionnaire. However, it is equally likely that dissatisfied individuals would take advantage of the opportunity to air their complaints. Moreover, the return rate for this study was quite good; of 40 questionnaires

disbursed, 17 were returned complete, 5 incomplete, and 5 were returned by the post office due to a lack of forwarding addresses, leaving 13 unaccounted. Those not responding may have done so for many reasons: some may have been too busy to respond, some may not have felt emotionally ready to examine their experience, others may not have received the assessment materials. It is also possible that some families did not respond because their perception of Edmarc's services was negative. However, the relatively large number of respondents makes it less likely that the small proportion of non-respondents were different or would have drastically altered the results of this study.

Another important consideration in the interpretation of this study was the validity of the findings. The lack of a true control group made it particularly difficult to discern whether adjustment differences for the Edmarc participants were a function of Edmarc's intervention, or were due to some other extenuating factors. Concerns relating to this question of internal validity were addressed in the following ways. First, demand characteristics were controlled. The Edmarc clients were contacted by mail, and were assured of the confidentiality of their answers. Responses were identified by numbers (names were not associated with the returned information), and were sent directly to the experimenter (who was not known by the subjects), rather than to Edmarc. Standardized questionnaires were included, and all subjects tested below

the established criterion for the social desirability measures.

In addition, efforts were made to locate comparison groups that were similar to the Edmarc group in terms of relevant bereavement factors. Some dissimilarity was evident in the age ranges of the three groups of parents (See Table 1), however, no literature was found that cited parental age as a distinguishing characteristic in the grief process. Also, the number of months since the child's death differed somewhat between the groups (See Table 1). A within-subjects analysis of the Edmarc participants found that the number of months since the child's death correlated with only 1 of 11 adjustment indices, indicating that his factor may not have been a significant confound in this study. In addition, some information was not available for the comparison groups (such as the subjects' level of religiousness); however, data from the Edmarc group indicated that these additional factors did not greatly influence their bereavement experience.

The second major portion of this study involved the Edmarc subjects' ratings of the helpfulness of various individuals and support services, excluding Edmarc. Clients also rated individual Edmarc service components. Parents' ratings of services and individuals other than Edmarc revealed a general decline in support after the child's death, with a significant decrease in the perceived helpfulness of physicians and social services (See Figure

1). Physicians were rated as being the most helpful overall, during the child's illness; however, they dropped abruptly into the lower half of rated services following the child's death. As described earlier, physicians may feel that their job has ended when a patient dies. Death represents a failure, an end, and the medical tradition is for the physician to turn his or her energy toward other needy patients. This may have a negative impact on the surviving family members who have come to depend on information and advice from their physician throughout their child's (often long-term) illness. Rowe and her colleagues (1978) found that,

> "Those mothers who had subsequent contact with a physician following their infant's death had a significantly higher level of understanding than those who received their information just during the hospitalization"(p.168).

They further found a direct correlation between the mother's lack of understanding and degree of morbid grief response. This cessation of contact may create a vacuum for the surviving family members, and further increase their sense of isolation and abandonment. This finding suggests the need for the continuity provided by programs such as Edmarc. Edmarc components surrounding the child's death (staff accompaniment to the funeral, the Edmarc Memorial Service, etc.) and the provision of long-term follow-up (bereavement

cards and other forms of continued contact) were consistently rated as being the most helpful.

Friends and family members were considered to be second most helpful (after physicians) during the child's illness, and most helpful following the child's death. This is somewhat contrary to experiences that are commonly cited by parents of terminally ill children. Often, friends and other family members feel uncomfortable, don't know how to help, and are afraid that they will only say or do something wrong. Consequently, their presence may gradually diminish. It is possible that the presence of support from family and friends influenced the Edmarc clients' decisions to undertake the responsibility of home hospice care, or that Edmarc teaches families how to access help that may be available but has remained untapped. This informal network of support does not, however, undermine the importance of the ongoing support provided by Edmarc staff, as evidenced by the high ratings given to these Edmarc components. The particular emphasis placed on Edmarc's support services following the child's death indicated that either more support was needed at that time, or that the support from previously existing systems (family, friends, physician, etc.) diminished over time. Also, the number of months of family involvement with Edmarc before the child's death was not correlated with any positive bereavement outcome. This may further indicate the value of Edmarc's (post-death) long-term follow-up services.

The role of social support in bereavement is an important one, and merits further discussion. Subjects rated the helpfulness of individuals close to them (such as family and friends) as higher than informational or service oriented alternatives (such as social services or public health agencies). It appears that the type of emotional support provided by such individuals is preferred and/or needed more than less personal, specific services. Edmarc's provision of emotional support was rated highly, although other services were rated more favorably. Perhaps this group of parents possessed an unusual availability of informal support resources, and hence, did not require as great an emphasis in that area from Edmarc. Also, it is possible that the ratings did not clearly reflect the subjects' feelings. Many respondents attached supplementary statements describing their appreciation for "their friends at Edmarc"; several stated that "the Edmarc people have been like family". One woman wrote that her experience with Edmarc was so positive that she "hopes someday to work as an Edmarc nurse". Statements such as these underscore the importance of social/emotional support.

Religiousness was another factor cited in the literature as mediating parental adjustment following the death of a child. The average rating of religiousness for the Edmarc group was 2.29 (on a 1 to 3 scale, with 1.0 designating "not at all religious", 2.0 corresponding to "somewhat religious", and 3.0 indicating "very religious").

This suggests a moderate level of religiousness for the Edmarc group. In addition, religiousness did not correlate significantly with any of the adjustment measures. Since information was not available about the religiousness of the GEI and FES non-home care groups, definitive conclusions cannot be drawn regarding the influence of religiousness. However, the failure to find significant results for the Edmarc subjects suggest that religiousness may not have been a distinguishing factor in their bereavement experience.

Anticipatory grief was a prominent consideration in the experience of bereavement that was consistently cited in the literature. It is difficult to draw conclusions regarding anticipatory grief, based on data from this study. No specific measure of anticipatory grief was administered, and clear differentiation of grief adjustment characteristics pertaining to levels of anticipatory grief cannot be ascertained. Some qualitative information is evident, however. All of the Edmarc subjects knew of their child's impending death, however, their acceptance was varied. For most, the anticipatory process enabled them to begin to work through their sense of loss gradually, and to maximize the remaining time that they had with their child. Edmarc assisted as both a provider of emotional support, and a facilitator in coping with many of the unpleasant tasks associated with death--such as funeral planning. It was in this capacity that the most visible evidence of inter-subject variability was found. Most of the respondents

rated funeral preparation assistance (prior to the child's death) as very helpful. However, for some parents, the prior knowledge of their child's impending death only seemed to increase their bitterness and strengthen their determination to "prove the doctors wrong" (i.e., to show that their child was not really terminal). They resisted the idea that their child was going to die, and resented any effort to discuss or plan for such an occurrence. For these individuals, anticipatory grief may have been delayed. However, most hospice participants accepted the eventuality of their child's death, and expressed appreciation for Edmarc's efforts. It would be interesting to compare those who accepted their child's terminal diagnosis with those who did not, in terms of their bereavement experience--do those who actively fight the diagnosis experience more denial, or possibly, guilt? It was not possible to make such comparisons of the subjects in this study, since almost all of the Edmarc clients were aware of the seriousness of their child's illness, and accepted their terminal prognosis. Also, no specific measures of the experience of anticipatory grief currently exist.

Guilt was another important factor in the bereavement literature. The present study found a significant relationship between the age of the child at death and the parents' level of guilt: as the child's age increased, the parents' guilt level increased. Possibly, the bond that grows over time between parents and children produces an

increased attachment and sense of responsibility, and results in higher levels of guilt following the child's death. Also, as children grow, they come into their own as people, and parents may be more aware of what illness has caused their child to miss. The realization that their child will never be able to do the things that the parents have done may produce this greater sense of guilt.

The results of this study indicated that the Edmarc subjects' experience of guilt may have differed somewhat from that of many grieving parents. Statistically significant results were not found differentiating the hospice from non-hospice clients on the guilt scale of the GEI. However, additional qualitative information indicated that important differences did exist between guilt experiences of the Edmarc clients and that which is typically experienced by bereaved parents. First, marital difficulties, a common consequence following the death of a child, were not found among the Edmarc subjects. In fact, spouses were rated as being among the most helpful individuals and services, both during the child's illness and following his or her death. This family harmony may have been promoted by Edmarc's support of the entire family unit, and by the cohesion gained through working together (caring for the ill child at home).

Another common aspect of guilt, the loss of control and resultant feelings of helplessness, also seems to have differed subjectively for the Edmarc individuals. Again,

statistical significance was not found; however, the majority of the participants related (under the generic "additional comments" section of the PRPQ) their feelings of personal satisfaction and inner peace over having enabled their child to die at home. They further stated their indebtedness to Edmarc for providing the emotional support and professional assistance needed to enable them to keep their child at home. Statistical significance notwithstanding, it was evident from the majority of the Edmarc subjects' responses that the home health care experience had greatly reduced their subjective experience of guilt.

A final bereavement factor is the passage of time. Prior research suggests that the passage of time facilitates the grieving individual's recovery (Rowe et al., 1978); Lauer, Mulhern, Wallskog, & Camitta, 1983). This study did not find any areas of grief adjustment that were associated with increasing amounts of time. In fact, one aspect (death anxiety) was found to increase over time. These results may indicate that a sufficient length of time had not passed for the Edmarc subjects to begin the recovery process. Death anxiety may have increased over this period of time because the parents have had the time to recover from the initial shock and despair over their loss, and their emotions have evolved into feelings of anxiety. Again, these results suggest the individual nature of the bereavement experience. It is therefore, not appropriate to expect bereaved parents

to consistently exhibit specific responses at specific treatment or time intervals.

In conclusion, the major predictions of this study were not supported--significant differences were not found between the home health and non-home care groups. While these results may reflect similar levels of adjustment to the death of a child for both groups, a number of potential confounds have been identified and discussed throughout this paper. It is important to keep in mind that the issue of experimental control requires special consideration in naturalistic settings. When dealing with "real life" populations it is not possible to achieve the same level of control over individual differences as in analogue or laboratory studies. This is particularly true when working with a small population base (such as parents who participated in home health care for their terminally ill child), where there is little room for manipulation. However, this element of realism adds a unique dimension of validity which is often difficult to achieve in simulated experimental settings. The fact that these subjects had actually undergone the bereavement process, and were thus describing their own grief responses (rather than merely projecting what their responses would be, as in an analogue study) increases the potential application and generalization of their responses to other bereaved parents.

Perhaps the most important criterion for determining the overall impact of Edmarc's program is the client's

direct evaluation. Subjects consistently gave Edmarc the highest rating, and included personal statements of recommendation, referring to Edmarc staff as "friends" and "like family". Several subjects stated that they "couldn't have made it without Edmarc", and asked that their gratitude be communicated to Edmarc. Such consistently positive endorsement speaks highly of the Edmarc program and staff.

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Appendix A

EDMARC, INC.

Parental Reactions and Perceptions Questionnaire

Name_____

1. Please answer the following questions about your child who died: Sex_____ Date of birth_____
Date of death_____Diagnosis_____
_____

2. Please describe the following aspects of your family:
Marital Status: Single___ Divorced ___ Married ___
Widowed___
If married, date of marriage _____
If divorced, date of divorce/separation _____
If widowed, date of death _____
If married, present ages of husband ___ and wife ___
Number of other children in family _____
Religious affiliation when child was alive (be as specific as you care to be) _____
How religiously active are you and your spouse? (circle one)
Not at all Somewhat Very

3. When did your family become involved with EDMARC?_____
How were you referred to EDMARC?_____

4. We want to know more about the problems you faced during your child's illness, and since his or her death. Please indicate which agencies and people were of help to you.

Helpfulness:	During Illness			After Death		
	Not at all	Some-what	very	Not at all	Some-what	very
1. Parents	_____	_____	_____	_____	_____	_____
2. Friends	_____	_____	_____	_____	_____	_____
3. Husband /Wife	_____	_____	_____	_____	_____	_____
4. Other Family Members	_____	_____	_____	_____	_____	_____
5. Minister	_____	_____	_____	_____	_____	_____
6. Physician	_____	_____	_____	_____	_____	_____
7. Public Health Dept.	_____	_____	_____	_____	_____	_____
8. Public Schools	_____	_____	_____	_____	_____	_____
9. Social Services	_____	_____	_____	_____	_____	_____
10. Others (list)						

5. The following items refer to EDMARC. Please indicate how helpful each item was to you, on a scale of 1 to 3 (1 = Not at all, 2 = Somewhat, 3 = Very much).

	How helpful was this? (1-3)	Did not use/receive ( )
a. Nursing assistance (in taking care of your child)	____	____
b. Physical therapy	____	____
c. Occupational therapy	____	____
d. Speech therapy	____	____
e. Religious support	____	____
f. A qualified person to stay with your child (so that you could take a break)	____	____
g. The professional skill level of EDMARC staff	____	____
h. The personal, caring relationship between EDMARC staff and you family	____	____
i. 24-hour nurse availability	____	____
j. Emotional support for your ill child	____	____
k. Emotional support for your other children	____	____
l. Emotional support for you & your spouse	____	____
m. Being put in touch with other parents in your situation	____	____
n. Funeral planning assistance	____	____
o. Having someone from EDMARC with you when your child died	____	____

p. Having someone from EDMARC at your child's funeral _____ _____

q. EDMARC memorial service _____ _____

r. Continued contact from EDMARC staff after your child's death _____ _____

s. Bereavement gifts _____ _____

t. Cards on holidays _____ _____

u. Christmas caroling _____ _____

6. Overall, how would you rate the services you received from EDMARC?

Not Helpful Helpful Very Helpful

7. If you have any additional comments/suggestions regarding the EDMARC program, please describe them below.

Table 1

Characteristics of Edmarc, GEI, and FES Subjects

Measure	Home Care			Non-home Care				
	Edmarc Group (N=19)			GEI Group (N=192)		FES Group (N=20)		
	Mean	Median	Range	Mean	Range		Median	Range
Age of Parents	34	35	23-52	52	*		41	23-54
Age of child at Death	6.88	6	1-18	*	*		10	2-18
Months Since Death	19.7	16	3-41	*	1.5-12		13	3-28
Religiousness	2.29	3	1-3	*	*		*	*

*Medians were not available for the GEI comparison group; means were not available for the FES comparison group.

Note: GEI comparison data were obtained from a 1985 study (Sanders, Mauger, & Strong). FES comparison data were obtained from a 1983 study (Mulhern, Lauer, & Hoffman).

Table 2

Means and Standard Deviations of

the Grief Experience Inventoy

Scale	Edmarc Participants (N=17)	SD	Non-home Care (N=192)	SD	P*
Denial	2.06	1.74	2.45	1.85	NS
Atypical Responses	6.29	3.90	6.60	3.48	NS
Social Desirability	4.77	1.25	4.38	1.32	NS
Despair	5.47	3.17	7.37	4.93	NS
Anger/Hostility	4.35	2.71	4.66	2.64	NS
Guilt	1.82	1.67	2.07	1.78	NS
Social Isolation	2.18	1.13	2.53	1.87	NS
Loss of Control	5.29	1.61	5.48	2.03	NS
Rumination	5.64	2.55	5.24	2.50	NS
Depersonalization	4.77	1.64	4.80	2.14	NS
Somatization	5.24	3.09	5.65	3.95	NS
Death Anxiety	5.77	1.96	5.79	2.38	NS

* Two-tailed probabilities; $p<.05$.

Note: Data for the non-home care group were obtained from a study by Sanders, Mauger, & Strong (1985).

Table 3

Means and Standard Deviations of the Family Environment Scale

Scale	Edmarc Participants (N=17)	SD	Non-home Care (N=20)	SD	P*
Relationship dimensions:					
Cohesion	50.29	18.12	44.89	14.72	NS
Expressions	45.35	12.79	47.47	21.12	NS
Conflict	44.94	9.96	43.47	12.13	NS
Personal growth dimensions:					
Independence	46.88	16.00	54.57	11.12	NS
Achievement Orientation	50.88	12.38	51.58	11.04	NS
Intellectual-Cultural Orientation	47.00	11.97	43.84	13.96	NS
Active Recreational Orientation	48.24	14.52	41.37	11.72	NS
Moral-Religious Emphasis	58.18	8.13	54.32	8.07	NS
System Maintenance dimensions:					
Organization	52.94	12.03	48.63	13.69	NS
Control	49.18	10.45	50.74	15.93	NS

*Note: Two-tailed probabilities; $p<.05$.

Table 4

Correlations Between Bereavement Factors and Grief Adjustment Indices

Adjustment indices*	Bereavement factor			
	Months since child's death	Child's age at death	Family religiousness	Months involved with Edmarc before death
Denial	-.17	-.29	.37	-.14
Atypical responses	.11	-.02	-.32	.40
Despair	.24	.13	-.19	-.05
Anger/ hostility	.20	-.25	-.28	.00
Guilt	.12	.52**	-.05	.03
Isolation	.35	.19	-.39	.10
Loss of control	.15	.37	-.05	-.28
Rumination	.04	.39	-.01	-.13
Depersonal-ization	.21	.14	.04	.05
Somatization	.22	.12	-.19	.20
Death anxiety	.52**	.28	.16	-.41

Note: $n = 17$

*Measured via the Grief Experience Inventory (Sanders & Mauger, 1979).

**$p<.05$; all other correlations were nonsignificant ($p>.10$).

Table 5

Edmarc Subjects' Mean Ratings of Helpfulness

Factor	Helpfulness During Child's Illness	Helpfulness After Child's Death
Parents	2.29	2.45
Friends	2.42	2.50
Spouse	2.50	2.50
Other Family Members	2.50	2.39
Minister	2.28	2.19
Physician	2.83	1.82
Public Health	1.31	1.19
School System	1.63	1.44
Social Services	1.76	1.44

* Rated on a scale of 1 (not helpful) to 3 (very helpful).

Note: N=22

Table 6

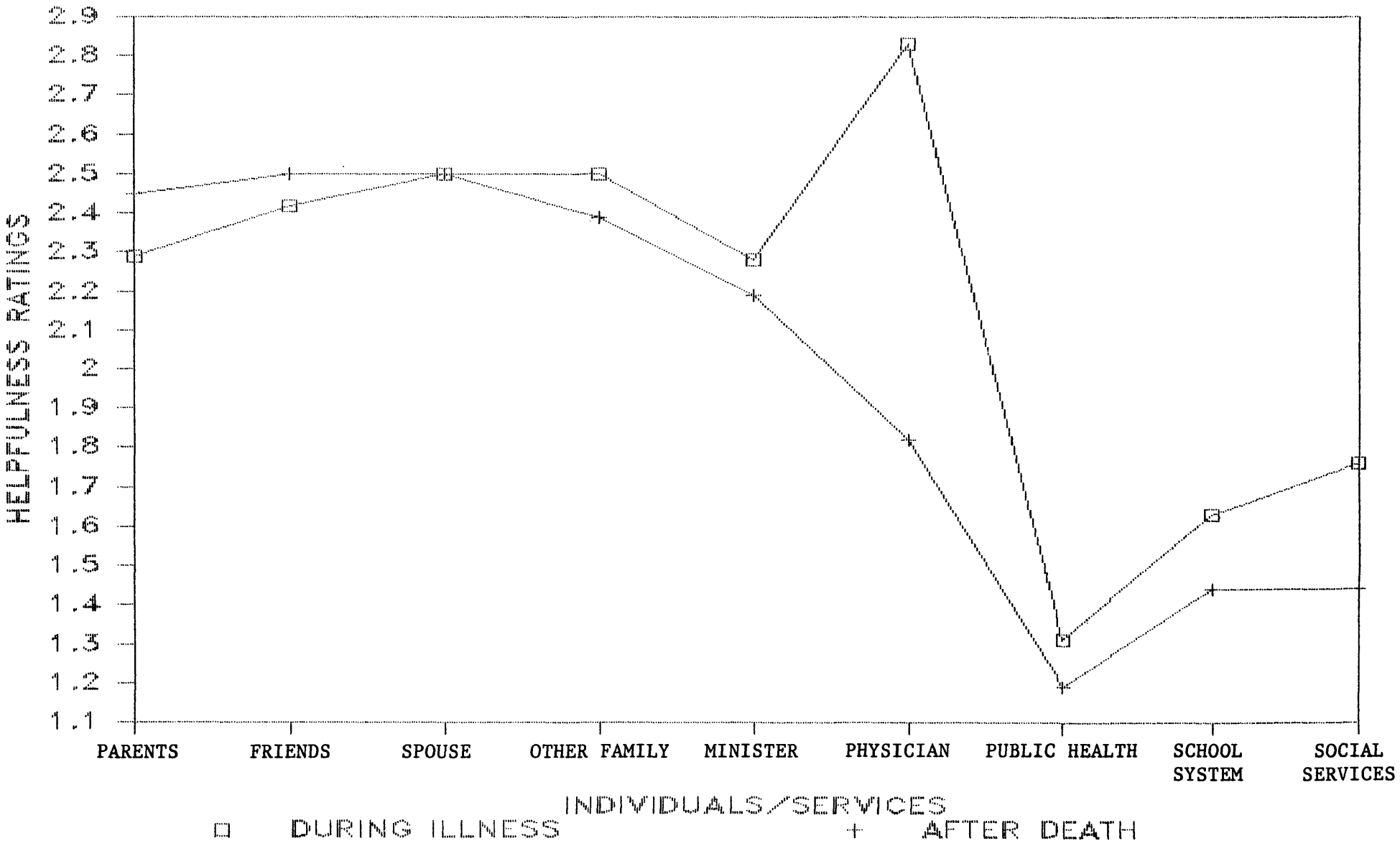
Edmarc Subjects' Mean Ratings of the Helpfulness of Edmarc Services

Edmarc Service	Ratings	Applicability
Hospice Services(during illness):		
Nursing Care	2.82	100%
24 Hour Nurse Availability	2.83	55%
Physical Therapy	2.71	32%
Occupational Therapy	2.50	18%
Speech Therapy	3.00	4.5%
Religious Support	2.56	73%
Putting Clients in Touch with Other Parents	2.46	59%
Respite Care	2.57	64%
Area Composite	2.66	
Quality Aspects:		
Professional Skill Level	2.86	100%
Personal Care Aspects	2.82	100%
Area Composite	2.84	
Emotional Support Components:		
Support for Ill Child	2.76	95%
Support for Other Children	2.50	73%
Support for Parents	2.68	100%
Area Composite	2.66	
Services Surrounding the Child's Death:		
Funeral Planning	2.68	86%
Presence of Edmarc Staff at Death	2.65	77%
Presence of Edmarc Staff at Funeral	3.00	82%
Edmarc Memorial Service	2.80	68%
Area Composite	2.78	
Long-Term Follow-Up:		
Continued Contact After Child's Death	2.82	100%
Bereavement Cards	2.85	91%
Bereavement Gifts	2.80	68%
Christmas Caroling	3.00	77%
Area Composite	2.86	

Note: N=22
* 1 indicated "not helpful", 2 - "somewhat helpful, 3 - "very helpful"

Figure Caption

Figure 1. Perceived helpfulness as a function of time interval and service/individual.


HELPFULNESS RATINGS
2.9
2.8
2.7
2.6
2.5
2.4
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2.2
2.1
2
1.9
1.8
1.7
1.6
1.5
1.4
1.3
1.2
1.1
PARENTS
FRIENDS
SPOUSE
OTHER FAMILY
MINISTER
PHYSICIAN
PUBLIC HEALTH
SCHOOL SYSTEM
SOCIAL SERVICES
INDIVIDUALS/SERVICES
DURING ILLNESS
AFTER DEATH

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